DOCUMENT RESUME

ED 355 691 EC 301 921

AUTHOR Fullagar, Patricia; And Others

TITLE Communication, Coordination, and Cooperation: Perspectives on Service Delivery and Part H.
INSTITUTION North Carolina Univ., Chapel Hill. Carolina Inst. for Child and Family Policy.
SPONS AGENCY Special Education Programs (ED/OSERS), Washington, DC.
PUB DATE Feb 93
CONTRACT G0087C3065
NOTE 20p.
PUB TYPE Reports - Research/Technical (143)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS *Agency Cooperation; Agency Role; Child Health; Community Programs; *Delivery Systems; *Disabilities; *Early Intervention; Educational Legislation; Family Involvement; Family Programs; Federal Legislation; Government Role; *Health Personnel; Infants; *Medical Services; Opinions; Preschool Education; Public Policy; Toddlers; Trend Analysis
IDENTIFIERS Focus Groups Approach; *Individuals with Disabilities Education Act Part H

ABSTRACT

This study examines the health care community's perspective on the delivery of services to young children with special needs and to their families. Focus group discussions were held with 87 health care practitioners in 5 states to identify extant trends and patterns of current practices, problems, and concerns. In the discussions, health care providers devoted more time to a description of difficulties with availability and accessibility of resources than to any other topic. Family and social issues affecting the use of available resources were important topics, as was the need for a knowledgeable and experienced service coordinator whose responsibilities would include arranging and organizing necessary resources for individual families. The scenarios related by the health care professionals indicated that governmental policies or agencies may be actively interfering with meeting the challenge of family-focused and community-based care as legislated in Part H of the Individuals with Disabilities Education Act. (Contains 21 references.) (PB)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
☑ This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

ED355690

Carolina Institute for Child and Family Policy

COMMUNICATION, COORDINATION, AND COOPERATION: PERSPECTIVES ON SERVICE DELIVERY AND PART H

PATRICIA FULLAGAR
CONLETH CROTSER
JAMES J. GALLGAHER
FRANK LODA

The University of North Carolina at Chapel Hill

EC 301921

BEST COPY AVAILABLE

COMMUNICATION, COORDINATION, AND COOPERATION: PERSPECTIVES ON SERVICE DELIVERY AND PART H

PATRICIA FULLAGAR
CONLETH CROTSER
JAMES J. GALLGAHER
FRANK LODA

February, 1993

Carolina Policy Studies Program
NationsBank Plaza, Suite 300
137 E. Franklin Street
Chapel Hill, NC 27514
(919) 962-7374

Carolina Policy Studies Program is funded by the Office of Special Education Programs, U.S. Department of Education, Cooperative Agreement #G0087C3065. However, these contents do not necessarily represent the policy of the Department of Education and endorsement by the Federal Government should not be assumed.

EXECUTIVE SUMMARY

Policy makers and officials charged with the implementation of Part H of the Individuals with Disabilities Education Act (IDEA) will find this report useful in policy development and program design because it describes relevant experiences and perceptions collected from primary health-care providers across five states.

The primary proposition in the study on which this report was based was that the involvement of health-care providers was critical to the operation of an integrated, comprehensive system of multidisciplinary services. We conducted a search for extant trends and patterns of current practices, problems, and concerns, from the perspective of the health community and specifically of practitioners who were recognized as active in the field of health-care provision to the Part H population. Their descriptions include types of collaboration and obstruction that exist among health providers and between the health community and other human service providers as each of these groups strives to meet the complex needs of the population that is targeted by Part H of IDEA.

Focus group discussions were held with the health providers and these permitted identification of some of the independent variables that affect outcomes; in this case, development of policy that facilitates delivery of comprehensive, community-based services. The health-care providers with whom we met devoted more time to the description of difficulties with availability and accessibility of resources than to any other topic. Family and social issues that affected the use of available resources were important topics, as the needs of the family and its environment cannot be isolated from those of the child. The need for a knowledgeable and experienced service coordinator whose responsibilities included arranging and organizing necessary resources for individual families emerged as the keystone to establishing and maintaining links between families and resources.

While Part H of Idea encourages care that is family-focused and community-based, the scenarios related by these health-care professionals indicated that other governmental policies or agencies may be actively interfering with meeting this challenge. Moreover, the experiences related by the direct service providers suggest that significant modification of health, social, and economic structures may be required in order to provide the care that is needed, as well as to meet the challenges posed by Part H.

INTRODUCTION

Policy makers and officials charged with the implementation of Part H of the Individuals with Disabilities Education Act (IDEA) will find this report useful in policy development and program design because it describes relevant experiences and perceptions collected from primary health-care providers across five states. Policy recommendations follow from the data presented herein, and from the integration of these data with those in other published sources.

Part H of IDEA, originally enacted by the U.S. Congress in 1986 as Part H of P.L. 99-457, calls on the states to provide comprehensive, coordinated, multidisciplinary, family-focused, community-based services to infants and toddlers, age birth-to-three, who are developmentally delayed. States also may provide services to children who are at-risk for developmental delay. Although the U.S. Congress provided financial incentives to states to encourage participation in this endeavor, the primary financial responsibility remains that of each of the individual states.

The study on which this report was based was designed to describe the delivery of services both to children who are developmentally delayed and to their families from the perspective of the health community. This description includes types of collaboration and obstruction that exist among health providers and between the health community and other human service providers as each of these groups strives to meet the complex needs of the population that is targeted by Part H of IDEA.

BACKGROUND

In the United States, policy makers and educators have made a concerted effort to meet the educational needs of all children, including those with special needs. In the 1950s and 1960s numerous pieces of legislation were enacted that authorized funds for the education of children with special needs, for research on learning styles, and for teacher education (e.g., P.L. 85-926, P.L. 88-164, P.L. 89-10). More recently, in 1975, the passage of P.L. 94-142, The Education of All Handicapped Children Act, required appropriate education in the least restrictive environment for all children, ages 3 to 18. And in 1986, the U.S. Congress passed P.L. 99-457, which extended the provision of multidisciplinary services to children with developmental delay from birth through age 5 (Parts B and H of P.L. 99-457). In 1991, Congress reauthorized services to all children with developmental delay and combined P.L. 94-142 and P.L. 99-457 into one law known as IDEA.

Implementation of any law requires time and effort on the part of many people, agencies, and organizations. IDEA is a particularly complex law as it requires development of comprehensive and multidisciplinary services out of those that are fragmented, and agency interaction out of a system designed to operate on parallel tracks (Harbin, Gallagher, Lillie, & Eckland, 1990). At the time the present study was conducted, all states were participating in the development of strategies leading

toward implementation of IDEA. However, no state had realized this goal (Harbin, Gallagher, & Lillie, 1991).

In the meantime, young children, and their families required services. Health professionals serve infants and toddlers whether they are sick or well, and whether their development is normal or delayed. This statement is not meant to suggest that all young children are adequately served by health care providers. But prior to present efforts to develop a systemic approach to health and human services for young children and their families, health providers had been an early, if not initial, professional contact for parents.

At the Carolina Policy Studies Program (CPSP) we reasoned, and the literature supported (Blackman, Healy, & Ruppert, 1992; Hanft, 1988), that most infants and toddlers who were developmentally delayed initially had been identified and served by health care providers: namely, physicians and nurses. The experiences of health professionals as they achieved cooperation and collaboration, or confronted barriers with other professionals, with parents, with governmental agencies and professional associations, and with governmental and private third-party reimbursers, therefore, were being sought as important to policy developers as they designed and built a system of multidisciplinary, collaborative, interagency services that would implement Part H of IDEA.

RESEARCH DESIGN[1]

Purpose

The primary proposition in this study was that the involvement of healthcare providers was critical to the operation of an integrated, comprehensive system of multidisciplinary services. Indeed, Part H of IDEA included health-care in its definition of a comprehensive system of multidisciplinary services. In an effort, therefore, to search for extant trends and patterns of current practices, problems, and concerns, we sought the description from the perspective of the health community and specifically from practitioners who were recognized as active in the field of health-care provision to the Part H population.

Method

Focus group discussions, a technique that originated in the area of marketing research (Brodigan, 1992; Morgan, 1988; Morgan & Spanish, 1984), provided the method for collection of data. A major characteristic of focus group discussions is that the data produced are particularly reliable and relevant when participants are highly skilled, knowledgeable, and experienced about the topic or question of concern (Morgan; Morgan & Spanish). Moreover, as Marshall and Rossman (1989) have discussed, information framed by knowledgeable participants permits identification of independent variables that significantly affect the outcomes under question. In the case of this study, we sought factors that influenced delivery of comprehensive, community-based services.

---

[1]For greater detail, contact first author Patricia Fullagar at 312 Glenwood Drive, Chapel Hill, NC 27514-5918.

Source

We elicited data from physicians and nurses in five states, selected for participation based on geographic and cultural diversity, and for leadership in provision of human services, including health care. Four of the five states involved in this study were among the 14 states whose Part H fourth year applications had been approved (Harbin, Gallagher, & Lillie, 1991). Fourth year approval for Part H means that a state must have affirmed policies that allow for implementation and must have in place procedures for multidisciplinary assessments, development of Individualized Family Service Plans (IFSPs), and designation of service coordinators (Part H of IDEA, Sec 1475 (b1A). Provision of services specified in IFSPs is not required until year five, however.

Health care providers who were invited to participate in the discussions were recommended by parents and professionals who were involved in programs for young children with disabilities (e.g., state Interagency Coordinating Councils, local and state parent advocacy groups, state chapters of the American Academy of Pediatric). The criteria for recommendation specified that the health-care practitioners be those who were knowledgeable of and actively involved in providing services for children who were developmentally delayed or disabled. Knowledge of P.L. 99-457 was not a prerequisite.

Sample

A total of 87 health-care professionals participated and provided data. There were 57 (65%) pediatricians and neonatologists and 16 (18%) nurses or physician assistants; the remaining 14 (17%) participants were physicians with specialties not specifically related to young children. Most of the physicians were in private practice; others were in community or tertiary hospitals, or public health departments. The nurses were located predominantly in hospitals and health departments.

The group of participants was evenly divided by gender. The 15 nurses and the sole physician assistant were female. There were 44 (62%) male and 27 (38%) female physicians. Eighty-one (93%) participants were Caucasian and 6 (7%) were Asian. The ages of the participants ranged from mid-20s to late 60s, with the majority between ages 35 and 60.

Most of the health-care professionals in the study practiced or were employed in cities. Although representation was sought from rural areas, most physicians and nurses are found in urban areas (United States Congress, 1990).

Data were analyzed using the constant comparative method (Glaser & Strauss, 1967; Strauss & Corbin, 1990) of conceptualization and categorization of information according to emerging themes and patterns. Cross-group data analysis revealed common trends that transcended state and regional boundaries and suggested themes that were national in scope. Within the themes, independent variables were identified that affected the outcomes of comprehensive, community-

based health care.

FINDINGS AND DISCUSSION

Many very young children, and especially infants, who are identified as developmentally delayed, have significant medical requirements and even may be characterized as medically fragile. Many require long term comprehensive services. Thus, it was not surprising that the health-care providers with whom we met devoted more time to the description of difficulties with availability and accessibility of resources than to any other topic.

Family and social issues that affected the use of available resources were important topics, as the needs of the family and its environment cannot be isolated from those of the child. The need for a knowledgeable and experienced service coordinator whose responsibilities included arranging and organizing necessary resources for individual families emerged as the keystone to the establishment and maintenance of links between families and resources. These themes, which are graphically depicted in Figure 1, are addressed below.

RESOURCES

Professional Resources

Infants or young children who are medically fragile often require acute medical attention in a tertiary-care center. While the health care providers expressed confidence about the quality of professional care provided in tertiary hospitals, the providers also conveyed considerable concern for the overall development of the child and for the development of a relationship between the family and the child. The concern for overall development included the desire to see the child enter the home and community-based setting as quickly as possible. The discharge from a tertiary-care facility often was delayed, however, by the paucity of community-based professionals.

> The ... tertiary care nurseries will not discharge a baby without having identified a care provider ... nurse ... physical therapist, also (Pediatrician in private practice)

Community-based medical generalists. The solution to the problem of locating competent and appropriate community-based medical services most often seemed to be a function of informal communication among professionals. Physicians spoke of networks that existed largely as a function of practicing in the same state in which they had trained. These networks enabled medical staff in tertiary-care centers to have first-hand knowledge of community-based physicians. It also allowed direct-care providers relatively quick access to highly trained sub-specialists located in training and tertiary care facilities.

Community-based medical sub-specialists. The issue of finding community-based sub-specialty medical care seemed to be a pervasive one which affected medically fragile children as well as those who were medically stable. Either sub-

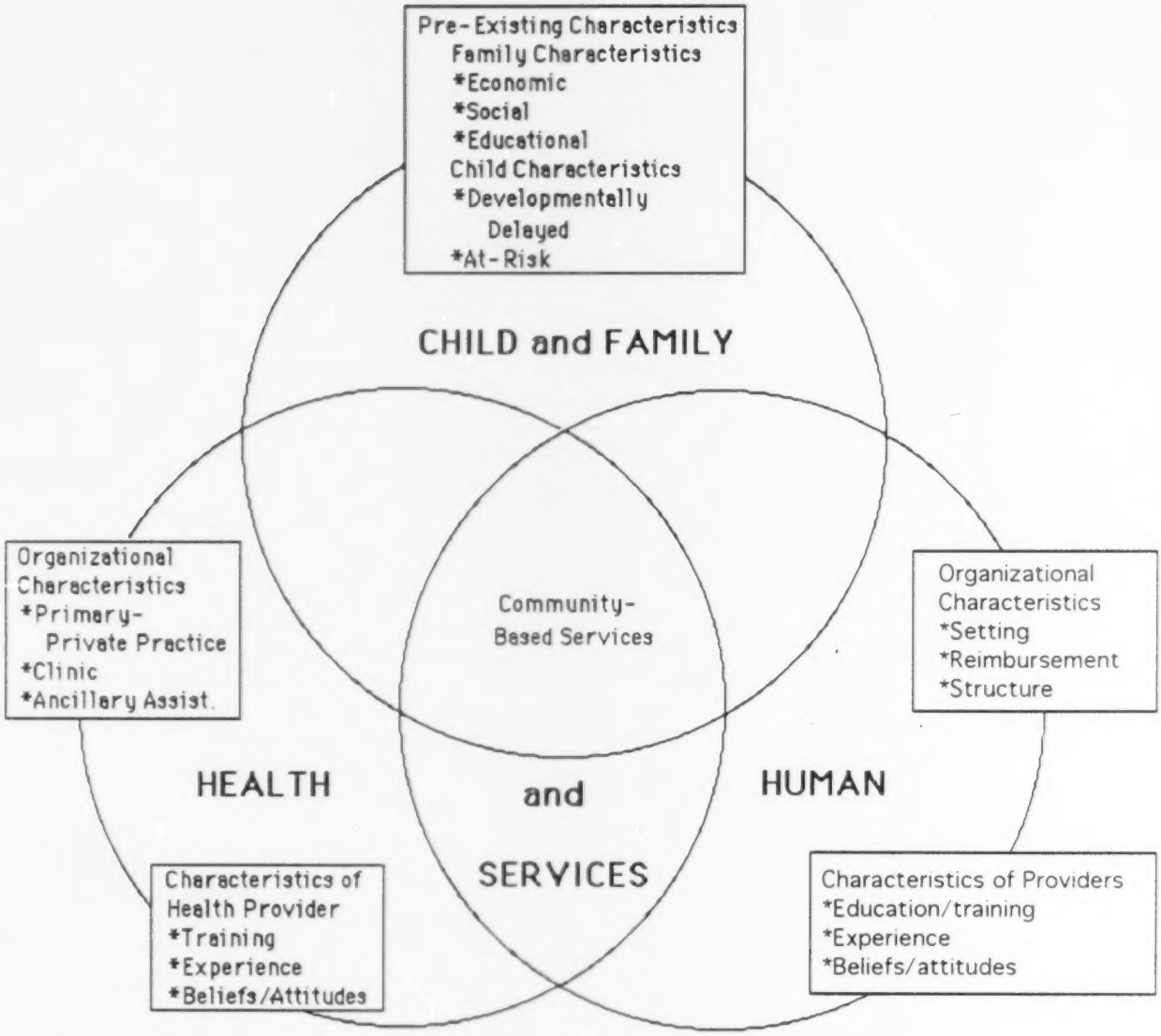

Figure 1: Factors Affecting Comprehensive, Community-Based, Multidisciplinary, Family-focused Services

specialists were not available in many communities or their training was not appropriate to the particular needs of infants and toddlers. State-of-the-art medicine utilizes highly sophisticated techniques, procedures, and technologies that change rapidly and are likely best known to those sub-specialists who were recently trained. Pediatricians spoke of reluctance to refer patients to a sub-specialist whose training was not recent or whose training was more appropriate to a different segment of the population (e.g., adults or older children).

There are, moreover, only a relatively small number of medical sub-specialists trained in the care of infants and very young children who are developmentally delayed, and these practitioners are concentrated in teaching hospitals and tertiary care facilities. In some instances, specialized medical teams traveled to local communities bimonthly or quarterly. Outreach consultation by medical sub-specialists to community-based physicians did not seem to occur frequently or with great regularity, however. While such an arrangement provided access to highly skilled and knowledgeable practitioners, several health-care professionals cited the inadequacies of such an arrangement in terms of providing comprehensive services. Among the problems mentioned were the lack of a long-term relationship between client and professional, which increased problems of continuity and communication; and lack of ready access to sub-specialty expertise when needed.

Community-based non-medical professionals. The difficulty of locating non-health human service providers with appropriate expertise was also a major frustration among the physicians and nurses who participated in the study. Two major problems expressed by the health providers were the difficulty in evaluating the level of professional competence and quality of care provided by allied health and non-medical professionals, and the transient nature of non-health and allied health professionals.

Many physicians expressed concern over knowing when to recommend other professionals, such as speech or physical therapists or early interventionists, as well as in understanding the amount of therapy that might be advisable.

> I also have a hard time as a pediatrician wondering how much does this [child] need. I'm not sure how much physical therapy a child really needs. I don't know. (Neonatologist)

The causal nature of the transience among non-health human service providers appeared to the discussion participants to be related to interacting factors. Financing for non-medical human services (e.g., specialists in early intervention; speech, physical, and occupational therapy; and social work) was relatively low, was not consistent (the positions disappear at times), and there was a high frequency of turnover among individuals filling these positions. The discussants suggested that this combination of problems might be related to financing and to lower professional status.

> Children's services do not pay as well as many adult-oriented services, particularly physical therapy. And so it's hard to attract people .... (Developmental pediatrician)

Relationships between health care and non-medical care providers that existed and functioned well were described as community-based and facilitated through informal networks that were formed over time. The frustration related to the potential for turnover and lack of continuity in the relationship, however, was expressed frequently. Moreover, the health providers stressed the need for a professional who could communicate and coordinate services among a variety of professionals and between professionals and families.

Service Coordinator. When a child's disability required continued involvement from multiple sub-specialties within the medical community, as well as from professionals in allied health fields (e.g., physical therapy, speech pathology) or education (early intervention), a two-tiered model of service coordination was described by the health care providers. The primary-care physician provided many decision-making functions and coordinated the efforts of physicians who supplied sub-specialty expertise.

> The non-physician case manager is at a serious disadvantage. It takes a physician to be able to stand up to ... other physician sub-specialists. (Pediatrician in a tertiary care/teaching hospital)

Another professional (e.g., early interventionist, nurse, social worker), in cooperation with the physician, handled the operational coordination of services among all professionals involved, among other agencies and programs, consulted with the family, and assisted with paper work (e.g., reimbursement forms, referrals, feed-back).

> I've got a child associate who works with me .... She's got the training ... to have most of [service coordination] collated. (Pediatrician in private practice)

The major problem in providing a service coordinator was funding. The professional activities of a service coordinator often were not an allowable charge for reimbursement. Only in larger private practices or in community hospitals was the demand deemed sufficiently high to support such a position as a full-time role. In one community that was represented in the focus group discussions, a system of communication, coordination, and cooperation between primary-care physicians and public health nurses was gaining strength. In this instance, public health nurses incorporated the role of service coordinator into their traditional duties. However, in numerous states, the time spent on case coordination was not funded under the reimbursement systems of many private insurers, as well as under Medicaid.

Constancy and continuity of primary care physicians. Most young children with developmental delays are not classified as medically fragile, nor do they require intensive medical treatment or hospitalization. The discussants did report, however, that families continually sought out the advice of physicians, even on topics not specifically related to matters of physical health (e.g., social-emotional development, early intervention). Several reasons for this phenomenon were suggested, one being that, physicians were often the first type of professional who assisted the family. The primary reason expressed, however, was that physicians provided a high degree of constancy or continuity, because they had a lower rate of professional

attrition and mobility than did many other types of human service providers. A source of concern that was expressed in these discussions was lower salaries, as an underlying cause of higher attrition and mobility among non-physician, human service providers.

Programmatic Resources

Children with developmental disabilities require complex programs for evaluation and treatment, as well as the services of highly skilled professionals to staff these programs. Many of these children require multiple types of services and comprehensive approaches that encompass physical, emotional, developmental, and family needs. Comments from the health care providers suggested that comprehensive services were rarely found outside of large, urban communities. Even when programs were available, there often were waiting periods of six months to a year. This suggested that levels of funding and/or levels of staff availability were not adequate to meet the demand for service.

Center-based vs. home-based services. Discussants frequently identified need for community-based programs that offered a wide array of services and alternative models for providing care. Many families wish home-based treatment programs for their infant, whereas others want center-based programs or ones that combine features of each. Most of the health care providers who participated in our groups advocated high-quality, center-based care and treatment at the community level. The practitioners felt that in this way comprehensive, multidisciplinary programs and services could be made available at a reasonable cost and in an effective manner. Two basic models of center based treatment were put forth by these health care providers: clinic and daycare based treatment centers.

Clinic-based care. The one most often described was a clinic similar to a tertiary-care hospital, where a wide variety of medical sub-specialists, as well as professionals in allied health fields, could be located. Social workers, educators, early interventionists, and psychologists also might be available in larger medical complexes. Availability, access, and quality control of professionals were viewed as enhanced in a clinic setting. Families, of course, would have to travel to clinics, and it was acknowledged that this would continue to be a problem for many families, particularly rural, inner city, and poverty level families. Mobile units that could provide service on an itinerant, outreach basis to neighborhoods or smaller communities were discussed, also.

Day-based care. Another model was more along the lines of a daycare facility. Most families with young children have at least occasional need for child care. Discussed were situations (e.g., appointments and obligations) where the presence of a child or infant is neither appropriate nor desired. Also both parents might be employed outside the home or the family might be headed by a single parent who worked. Arcia, Keyes, Gallagher, and Herrick, 1992, for instance, have documented that over half of the women with children under 5 years of age are in the workforce. Caregivers are not easy to find; often, as was mentioned by the participants, the greater the need for specialized care, the more difficult it is to find qualified and appropriate care.

Moreover, the pressure of constant care of an infant or toddler who is delayed, ill, or disabled places numerous stresses on parents. Many of the health-care professionals expressed concern over the responsibilities faced by parents of children with developmental disabilities. They spoke of depression among parents, of breakdowns in family life, and of families dissolving. They discussed situations in which optimal care of the child who was developmentally disabled was diminished when families were faced with conditions of poverty, lack of education, isolation, or cultural diversity. In conditions such as these, in which families are stressed by many difficulties, a child who is delayed is but one of many critical problems.

A system of day-and respite-care provided through the services of highly-skilled staff was discussed in our focus group sessions and was viewed as providing the relief that was needed by many parents, even those who were coping extraordinarily well. Family-centered care relies heavily on individual responsibility; it places the burden of all facets of care and development squarely on the shoulders of the family. Day-care can provide needed support for families, as well as ancillary services that assist families in the fulfillment of the needs of their child and in acquisition of the resources necessary to meet those needs. It also can provide the locus for coordination of many different types of services. Examples of situations in which multidisciplinary teams of professionals went out to center-based settings where children were centrally located were cited. In this model, young children were receiving comprehensive care that included early intervention and well-child health-care, as well as specialty services from health and allied health professionals. In programs of high quality, families had the security and comfort that accompanied the knowledge that their children were well-cared for.

Structural Resources

In addition to human and program resources, the participants cited the need of accommodation from a variety of societal structures. Third-party insurance coverage and transportation for families were issues emphasized in the discussions. Insurance and transportation are needed by all families, and each is of critical importance for those whose lives are compromised by conditions of poverty or lack of education.

Coverage. First, the participants noted numerous problems with the process of determination of eligibility for Medicaid. The financial means tests were reported to be interpreted in an idiosyncratic manner and to require incredible amounts of documentation from applicants. Also, there was considerable discussion about a lack of consistency in the services covered by insurance companies, including Medicaid. Variations in coverage and in interpretations of regulations were described as common occurrences, not only within a given state, or among various regions or counties within a state, but even within a specific office or agency. There were reports of informal networks where families were advised to "talk only with Joe, but never with Sam," or "to apply through Office Y rather than Office X."

A widespread belief was expressed that poverty and near-poverty level patients had a greater number of health and health-related problems; that a greater percentage of the problems were serious in nature; and that adequate reimbursement for time, effort, and complexity of treatment did not exist. Persistence in seeking reimbursement from third party payers often was rewarded, but those in

the discussion groups noted numerous negative effects on the care received by children and families, and on the administrative costs incurred by providers. For instance, many of the private, direct care providers who were involved in this study either limited the number of Medicaid patients served or refused to provide care to these patients.

Families whose income prohibited Medicaid eligibility, but whose employment did not result in sufficient medical insurance coverage, formed the group with the most critical problems. Emergency room treatment was the most prevalent source of health care. Therefore, these "grey area families" were seen for isolated, acute needs, not for preventative or health promoting reasons.

The inconsistency and insufficiency of coverage for non-health human services received a greater amount of attention from the discussants than did problems with coverage for health needs. Repeatedly, the need for financial coverage for case managers, social workers, and early intervention specialists was noted. When coverage for non-health services did exist, the inadequacy of the coverage was cited as negatively influencing the quantity and quality of care provided.

Transportation. Access to care received by children and families emerged as a major concern. As previously discussed, many services needed by young children with developmental delays are available only in urban areas or areas associated with tertiary care centers. Not all families have dependable or readily accessible transportation: some parents are teenagers who are too young to have a driver's license; some families must rely on neighbors or extended family members for transportation, which is usually erratically available; mass transit can result in delays, disruptions, multiple transfers, and missed connections for urban families who must rely on it.

IMPLICATIONS

Objectives of IDEA

Comprehensive, community-based care. The primary objectives of Part H of IDEA are to provide community-based services that are comprehensive and multidisciplinary, as well as family-centered. Community-based services increase the potential for equality of access by all who are in need of specialized care (Schorr, 1986) and continue the trend toward decentralized care (Hutchins & McPherson, 1991). Yet, as demonstrated by the present study and noted by Hutchins and McPherson, comprehensive resources that include health, allied and mental health, and early intervention are not available at levels sufficient to meet the demand in rural areas as well as in most local communities. This means that the goal of care that is readily accessible will remain largely unfulfilled for the foreseeable future.

Family-centered care. The authors of this legislation recognized the critical importance of participation by families in all aspects of their children's care and development. Family-centered care acknowledges the strengths of the family unit and encourages parent and professional partnerships that can be directed toward the enhancement of the child's development.

Family-centered care can provide an environment that is nurturing and highly conducive to obtaining maximum growth and development for each family member. The families with infants and toddlers who are developmentally delayed face many adjustments. They must learn to reconcile their expectations for a healthy child with the realities of a child who is ill, delayed, or disabled. They need to acquire knowledge about their child's condition, and about the medical and developmental treatment and prognosis of the disability or illness. Specialized techniques and skills may be needed in order to care for their child, and to monitor the care provided by others. Knowledge of health-care financing, insurance regulations and restrictions may become necessary. The means of gaining access to a variety of needed and desired services may become part of the parents' repertoire. All of this and more must be combined with routine responsibilities and obligations at home and in the community and workplace.

Our focus group discussants suggested that many families were stressed by their responsibilities. They expressed concern about the extent of support needed by parents and of the overall absence of any system through which to provide support for extenuating needs of families. The need for community based support for families at all socioeconomic and educational levels was noted, but attention focused on those at the lowest levels of education and economic attainment. The content of the discussions concurred with Healthy People 2000 (U.S. Department of Health and Human Services, 1990), which reported that low levels of education and socioeconomic status were associated not only with higher levels of developmental delay in infants and children, but also with a lack of attention to health and developmental needs, and concomitantly, with a lack of health insurance or any other means of securing services. The report concluded by noting that numerous social and economic intervention were needed to improve the education, health, social, and economic conditions of American children.

Coordinated Care. In Part H of IDEA, emphasis is placed on the interaction between the families of children with developmental delays and professionals from among a wide range of disciplines. The law recommends coordination and integration of services through the efforts of the service coordinator. The role of service coordinator was identified by the health care providers who participated in the focus groups as the key to a family's successful entry to, and maintenance within, a family-oriented system of multidisciplinary services including health care. Analysis and synthesis of actual experiences related by health care professionals resulted in a description of the service coordinator as one who responds to the needs of the family while recognizing the family's own resources and abilities; possesses knowledge of community, programmatic, and financial resources; understands ethnic and socioeconomic diversity; and communicates with parents and professionals.

Yet, in most instances described, coordination occurred in an informal manner that was often haphazard and erratic. It was conducted by individuals who were stretched beyond adequate functioning levels of time, energy, and expertise. This resulted in provision of services that were fragmented and less than optimal. While Part H of IDEA encourages care that is coordinated, the stories related by these health-care professionals indicated that other governmental policies or agencies may be actively interfering with meeting this challenge. Moreover, the experiences related by the direct service providers suggested that significant modifications of

health, social, and economic structures may be required in order to provide the care that is needed, as well as to meet the challenges posed by Part H.

RECOMMENDATIONS

There are many challenges to development of a viable system of services that includes health care. In the first place, there is no overall system of health care in the United States (W. T. Grant, 1987; Raffel, 1987). In addition, Americans have been ambivalent about whether there should be such a system of health care (W. T. Grant).

The lack of a system has minimal effect on healthy, affluent citizens. However, lack of a system can leave the more vulnerable segments of our society (poor, elderly, delayed) without adequate health care (W. T. Grant) as the uneven distribution of professionals and programs results in severe shortages in rural areas and in inner cities. In addition, systemic problems in numerous other areas affect access to and provision of human services: transportation, coordination of care and services, cultural and communication differences, poverty, financing of programs and services.

Medicaid, which was established under Title XIX of the Social Security Act Amendments of 1965, was conceived as a means by which the poor of this nation could gain access to health care, and it has had an impact on numerous aspects of health care, such as lower infant mortality rates and increased childhood immunization rates.

Medicaid has rigid requirements for the types of treatment allowable under its reimbursement guidelines, however. Although more recently Medicaid policies have been adopted that ameliorated cognitive or social approaches, it, as well as coverage from private insurance providers, has been biased in favor of medical care that is procedural and away from health care that has a cognitive, social or emotional basis, such as developmental stimulation, counseling, or assistance with coordination of multidisciplinary care.

Human Service System. Wiener and Engel (1991) have suggested reform of the human service delivery system in terms of two broad options: incremental and radical. In the incremental system, governmental funding could be increased for existing programs, which continue to operate with existing financial and administrative structures. In the latter option, a two-tiered system of services would address a broader base of care than traditional health providers and programs provide. Other recently proposed models of health care also have moved in the direction of integrating health with education and other social factors such as services that include assistance with child development, nutrition, substance abuse, job training and education for parents, and budgeting of money and time (Sardell, 1990; Schorr, 1988).

This is much the same message conveyed by the physicians and nurses who contributed to this study. The argument for a special system dedicated to serving the poor and other hard-to-reach groups is that this group has a vast number of social, economic, and health problems that require the services of professionals who have

specialized training, knowledge, skills, and commitment (Sardell, 1990). Moreover the problems are interactive, not discrete. Improvement of health entails provision of prenatal and infant care that is preventative, a focus on social and living conditions, on education, on family and individual income, and on health care financing. In the final analysis, traditional approaches to improvement of health care for the poor and hard-to-reach portion of the population simply are too narrow or restrictive to achieve significant accomplishments.

The drama of the present is profound. There exists a distinct opportunity to proceed to new heights -- new heights that orchestrate humanity -- intellectually, morally, socially, and physically. At present, the path to those heights is not found at the national level. We, as a nation, are not prepared to pay for "other people's children" (Kozol, 1991). Perhaps, it is at the local, grass roots, community level that an integration of people and services can occur. It is at the local level where community-based, family-focused caring will occur. The drama may ultimately be played out by local citizens who believe that the strength of their community rests on the welfare of all of its members.

REFERENCES

Arcia, E., Keyes, L., Gallagher, J., & Herrick, H. (1992). Potential underutilization of Part H services: An empirical study of national demographic factors. Chapel Hill, NC: The Carolina Policy Studies Program.

Blackman, J. A., Healy, A., & Ruppert, E. S. (1992). Participation by pediatricians in early intervention: Impetus from P.L. 99-457. Pediatrics, 89, 98-102.

Brodigan, O. (1992). Focus group interviews: Applications for institutional research. AIR Professional File. Winter, No. 43.

Glaser, B., & Strauss, A. (1967). The Discovery of Grounded Theory. Chicago, IL: Aldine.

Hanft, B. (1988). The changing environment of early intervention services: Implications for practice. American Journal of Occupational Therapy, 42, 724-731.

Harbin, G., Gallagher, J., Lillie, T., & Eckland, J. (1990). Status of states' progress in implementing Part H of P.L. 99-457: Report #2. Chapel Hill, NC: The Carolina Policy Studies Program.

Harbin, G., Gallagher, J., & Lillie, T. (1991). Status of states' progress in implementing Part H of P.L. 99-457: Report #3. Chapel Hill, NC: The Carolina Policy Studies Program.

Hutchins, V.L., & McPherson, M. (1991). National agenda for children with special health needs: Social policy for the 1990s though the 21st century. American Psychologist, 46, 141-143.

Kozol, J. (1991). Savage Inequalities: Children in America's Schools. New York: Crown Publishers, Inc.

Marshall, C., & Rossman, G. G. (1989). Designing Qualitative Research. Newbury Park, CA: Sage Publications.

Morgan, D. L., (1988). Focus Groups as Qualitative Research. Newbury Park, CA: Sage Publications.

Morgan, D. L. & Spanish, M. T. (1984). Focus groups: A new tool for qualitative research. Qualitative Sociology, 7, 253-270.

Raffel, M. W. (1987). Health policy formulation in the United States. International Journal of Health Planning and Management, 2, 223-232.

Sardell, A. (1990). Child health policy in the U.S.: The paradox of consensus. Journal of Health Politics, Policy and Law, 15, 271-304.

Schorr, A. L. (1986). Common Decency: Domestic Policies After Reagan. New Haven: Yale University Press.

Schorr, L. B. (1988). Within Our Reach: Breaking the Cycle of Disadvantage. New York: Anchor Press.

Strauss, A., & Corbin, J. (1990). Basics of Qualitative Research. Newbury Park, CA: Sage Publications.

U.S. Congress, Office of Technology Assessment (1990). Health Care in Rural America. OTA-H-434. Washington, D.C.: U.S. Government Printing Office.

U.S. Department of Health and Human Services (1990). Healthy People 2000: National Health Promotion and Disease Prevention Objectives. Washington, D.C.: U.S. Government Printing Office.

Wiener, J. M., & Engel, J. (1991). Improving access to health services for children and pregnant women. Washington, D.C.: The Brookings Institution.

W. T. Grant Foundation Commission on Work, Family and Citizenship (1987). The forgotten half: Pathways to success for America's youth and young families.

Frank Porter Graham
Child Development Center
CB No. 8040, 300 NCNB Plaza
Chapel Hill, NC 27599